Patient safety incidents in advance care planning for serious illness: a mixed-methods analysis

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ABSTRACT

Objectives Advance care planning (ACP) is essential for patient-centred care in the last phase of life. There is little evidence available on the safety of ACP. This study characterises and explores patient safety incidents arising from ACP processes in the last phase of life.

Methods The National Reporting and Learning System collates patient safety incident reports across England and Wales. We performed a keyword search and manual review to identify relevant reports, April 2005–December 2015. Mixed-methods, combining structured data coding, exploratory and thematic analyses were undertaken to describe incidents, underlying causes and outcomes, and identify areas for improvement.

Results We identified 70 reports in which ACP caused a patient safety incident across three error categories: (1) ACP not completed despite being appropriate (23%, n=16). (2) ACP completed but not accessible or misunderstood between professionals (40%, n=28). (3) ACP completed and accessible but not followed (37%, n=26). Themes included staff lacking the knowledge, confidence, competence or belief in trustworthiness of prior documentation to create or enact ACP. Adverse outcomes included cardiopulmonary resuscitation attempts contrary to ACP, other inappropriate treatment and/or transfer or discharge.

Conclusion This national analysis identifies priority concerns and questions whether it is possible to develop strong system interventions to ensure safety and quality in ACP without significant improvement in human-dependent issues in social programmes such as ACP.

INTRODUCTION

Healthcare-associated harm poses a major threat to public health and well-being. Palliative care is not exempt from these risks. The World Health Organization (WHO) Universal Health Coverage draws attention to priorities for high-quality, safe palliative care in the last phase of life (ie, people in the last days, weeks or months of life). Discordance between patients’ preferences and care received in the last phase of life is common. Most people express preferences to die at home but in the UK, and many other countries, most die in hospital. Access to palliative care is not equitable. Patients receiving specialist care are more likely to die in their usual place of residence with lower symptom burden. Those not known to specialist services are more likely to die in acute hospitals. Numbers and proportion of deaths in hospitals are projected to rise. Ascertaining patients’ priorities to improve care and focus resources is paramount. Advance care planning (ACP) may help address these challenges.

ACP is a process of enabling patients to discuss and record goals and preferences for future healthcare with family and healthcare providers. UK and international professional guidelines recommend ACP. ACP can improve outcomes for patients and relatives without causing psychological distress. However poor uptake, inaccurate or inaccessible documentation, and variable evidence of benefits are concerns. A fundamental challenge is that ACP is an intrinsically complex, human-dependent social programme, making it difficult to define and measure, compare studies or synthesise results. In this study we conceptualise this challenge by using the United States Department of Veterans
Affairs (USDVA) Strength of Intervention scale term ‘human-dependent’ as our definition of processes which are necessarily reliant on the choices of individual people.\textsuperscript{21,22}

There remains uncertainty around quality and efficacy of ACP. Little research has focused on patient safety issues within ACP. As ACP is increasingly undertaken, it is important to understand types of patient safety incidents occurring and the underlying factors. Many healthcare systems have committed to learning from patient safety incident reporting systems to improve patient care. The National Reporting and Learning System (NRLS) is the repository receiving such reports from healthcare organisations and members of the public in England and Wales. A patient safety incident is defined as ‘an event or circumstance that could have resulted, or did result, in unnecessary harm to a patient’.\textsuperscript{23} Reports are written mostly by healthcare professionals and collated via local risk management systems. Each contains structured information about location, patient demographics and reporter perception of harm severity plus free-text descriptions of the incident, most also outline contributory factors and planned actions to prevent reoccurrence.

With all reporting systems, caution is required when interpreting data given uncertainties about reporting culture, such as under-reporting and reporter bias.\textsuperscript{24,25} However, value and utility of structured analysis of incident reports for the identification of improvement priorities, notably in under-researched areas of unsafe clinical practice, has been established.\textsuperscript{26,27} Policies promoting ACP over the last one to two decades have led to the design of multiple interventions seeking to target ACP. These include interventions to raise awareness,\textsuperscript{28–29} educate staff,\textsuperscript{30–31} employ dedicated staff\textsuperscript{32–33} and improve systems to share ACP.\textsuperscript{34–36} A significant evidence gap remains: we do not know if these solutions are targeting front-line experiences of process breakdowns or challenges, at all or in the most optimal way.

Aim
To explore and understand patient safety incidents in which ACP, or its absence, contributed to unsafe patient care in the last phase of life.

Objectives

To:
1. Classify and quantify types of ACP-related patient safety incidents, and their underlying causes through application of a theoretically derived a priori coding framework.
2. Describe and interpret themes and meta-themes in reports and use this qualitative analysis to identify data-driven themes to focus future improvement work.
3. Construct a driver diagram mapping empirically identified ideas for systems improvement derived from objectives 1 and 2.

METHODS

Data

Data were taken from all NRLS incident reports that were reported to have occurred between 1 April 2005 and 31 December 2015.

Sample selection

Electronic searching of free-text descriptions was conducted using synonyms of ACP (see online supplementary appendix) identifying 976 reports. Two clinical academics (TD and HW) read and identified reports focused on the last phase of life in which there was a patient safety incident attributed either to ACP or lack of ACP by the reporter. Seventy reports met these inclusion criteria, 906 were excluded (see figure 1). We used consensus clinical judgement to ascertain whether the patient was in the last phase of life alongside proxy indicators including mention of progressive or life-limiting illnesses, a death occurring with a ‘do not attempt cardiopulmonary resuscitation order’ (DNACPR) in place and if the patient was in a nursing home.

Analysis

The free text of each report was analysed by a clinician trained in root cause analysis (TD). An a priori coding framework was used to describe what happened (type of patient safety incident), reported reasons why the error occurred (contributory factors) and resultant harms (outcomes). The framework was theoretically derived previously by patient safety experts and clinicians and aligned to the WHO International Classification for Patient Safety.\textsuperscript{37} A random sample of 20\% of reports was independently reviewed (HW) and inter-rater reliability was assessed. Any uncertainty was discussed with a third reviewer (AC-S). We undertook descriptive analysis of the coded data to assess the most frequent incident types, contributory factors and outcomes. We then grouped the reports according to which stage of the ACP process the incident occurred (i.e. during creation, communication or application of ACP).

All reports with sufficient detail in the free-text fields were also analysed qualitatively using thematic analysis which is a method for identifying anticipated and emergent themes from data.\textsuperscript{38} It was used...
to critically analyse each reporter’s stance towards the incident, recognising that reports are socially constructed through the perspective of the reporter. Data-derived emergent codes were identified in vivo from the reports by TD and independently by SY. These codes were then integrated into themes (collections of interrelated codes) through discussion (TD and SY). This iterative method and the evolving codes/themes developed and followed established qualitative research principles.39 40

Synthesis

The mixed-methods analysis was integrated and synthesised in a driver diagram, an established quality improvement tool used to highlight priority areas for change41 (Figure 2). We have contextualised our findings by conducting focused searches to identify existing ACP interventions and evidence of efficacy.

RESULTS

Seventy incident reports were included. Of these, 50% (n=35) were reported to have occurred in acute hospitals, 27% (n=19) in care homes, of which 20% were nursing (n=14) and 7% residential care (n=5). The remaining 23% (n=16) occurred in private homes. No reports described hospice incidents.

Three main types of incident were identified:

1. ACP not completed despite being appropriate (23%, n=16).
2. ACP completed but not accessible or miscommunicated between healthcare professionals (40%, n=28).
3. ACP completed and accessible but not followed (37%, n=26).

Intercoder agreement for coding incident type was high with a Cohen’s κ co-efficient=0.82.

Each report was numbered 1–70 and quotes have been drawn for illustrative purposes. Free text reporting has been lightly edited (denoted by square brackets) for anonymity and comprehension.

ACP not completed despite being appropriate

In 16 reports (23%) the reporter believed ACP would have enhanced care and lack of ACP contributed to the incident. Most of these reports contained no evidence of ACP discussions or documents (14%, n=10).

Several demonstrated conflicts felt by clinicians between allowing natural death and feeling obliged to sustain life at all costs:

ECP [Emergency care practitioner] asked to attend call to administer analgesia to anaemic patient complaining of abdominal pain. Patient had refused to attend hospital. On arrival, patient was Cheyne-Stoking with little cardiac output. Son and daughter were in attendance but refused to let ECP commence life-saving procedures or to phone for back up. They...
stated that the patient did not want any intervention. ECP asked whether there was a living will and was told there was not. ECP informed family that he had an obligation to commence CPR [Cardiopulmonary Resuscitation] if needed but family adamant that this should not be done. ECP also stated would not give any analgesia as it would kill the patient and this could be seen as homicide. (report 3)

In six reports ACP discussions had taken place but were not documented or up to date:

- We rushed him onto the ambulance and onto the stretcher where CPR was started. The family expressed he had a living will that was due to be updated by the GP [general practitioner] with a DNACPR [Do not attempt cardiopulmonary resuscitation]. Until we could speak to GP we continued ALS [advanced life support]. GP clarified DNACPR had been discussed and that it would be ‘grossly inappropriate’ to continue. ROLE [Recognition of life extinct] performed. (report 43)

ACP completed and accessible but not followed
Twenty-eight reports (40%) described problems with effective communication. Most of these described documentation being lost, inaccurate or unavailable (27%, n=19). Transition of care was often a contributory factor. In 12 reports, ACP documents were unavailable following transfer of the patient as typified by the following example:

- Patient with [neurodegenerative disorder] attended Accident & Emergency – DNACPR form and living will brought in from home but not returned when patient discharged, therefore when patient suffered cardiac arrest at home DNACPR paperwork not available and [ambulance service] forced to perform full ALS treatment. As a result patient suffered the indignity in death that he had taken every step to prevent. (report 10)

In several reports ACP documents could not be located quickly enough during an acute deterioration resulting in inappropriate intervention such as CPR:

- After arriving and doing full CPR and ALS for 20 min the patient regained an output, no respiratory effort. The decision to move the patient to the ambulance was made at this point. After placing the patient in a chair to take downstairs the nurse in charge gave me a piece of paper and said I needed to read it, this was an advance decision to refuse treatment (ADRT). (report 22)

Five reports described breakdowns in verbal communication and two described problems with verbal communication and documentation. Poor handover between teams within a setting caused similar problems:

- Living will not handed over by MAU [Medical Admissions Unit] staff nurse so cardiac arrest call done and resuscitation CPR commenced. (report 21)

A further eight reports described failure to achieve preferred place of care. This was due to unavailability of hospice beds, community staff, medication or an inappropriate transfer to acute hospital for life-sustaining treatment:

- Patient admitted for diamorphine and hyoscine pump as nursing home unable to obtain drugs. Patient has a living will specifying not to admission to hospital. (report 9)

Resource constraints only accounted for five reports in which ACP was not followed; staff perceptions and interpretation of ACP was a bigger factor in this data set. Misunderstanding about what constitutes a valid ACP and how mental capacity is defined and represented in law was an underlying theme in many reports:

- I looked at the will noting that it was drawn up in [date: 1 year prior] and that it was not signed by a doctor or medical professional. I stated that the document was not binding and that it would be illegal for me not to treat the patient […] The daughter arrived and I was asked not to treat her mother. I informed her that I could not stop until the patient had the mental capacity to tell me to stop. (report 20)

Poor understanding of palliative care principles also caused some patient safety incidents. Here a misconception led to an inappropriate admission, despite the fact
the patient had made plans to die at home with an ACP
equipment and medication arranged:

Patient commenced on a syringe driver [date] as
terminally unwell. OOH [out of hours] GP called
out around 18.00 on [date] which resulted in patient
being admitted for rehydration (IV [intravenous]
fluids) as the family reported that they were told he
was in pain due to being dehydrated at this point the
patient was unable to drink due to his deteriorating
condition. Anticipatory medications were all
available in the house. (report 27)

Cross-cutting themes and consequences—interpretative
synthesis integrating mixed-methods findings
We identified some cross-cutting themes that were
present across the reports, regardless of whether the
patient safety incident was due to lack of ACP being
completed, communicated or enacted when needed.
Relatives commonly assumed they held authority to
make decisions on behalf of someone who lacked
capacity. This led to conflict with professionals whose
fear of medicolegal consequences arising from with-
holding interventions was evident. Words such as ‘obli-
gation’ and ‘forced’ were used in descriptions about
life-sustaining treatment or CPR, suggesting staff felt
pressure to provide treatments and lacked confidence
in assessing if ACP was applicable, and if they were
‘allowed’ to make decisions to withhold interventions.
‘Decision-maker availability’ created challenges
where front-line staff (mainly nurses and paramedics)
did not feel able to choose a palliative approach over
life-sustaining treatment (whether ACP was completed
or not) and had difficulty contacting a senior deci-
sion-maker (usually a GP, or other senior doctor).
‘Conflict between staff’ as to what course of action
should be taken was also present. This may reflect
different levels of palliative care experience but is
more likely to reflect the complexity of using ACP to
guide decision-making. Differing terminology used to
refer to ACP may have also contributed to ambiguity in
interpretation. There was evidence of staff confusing
ACP with DNACPR:

Ambulance crew misunderstood that presence of
Advance Care Plan was not necessarily indicative
of a DNACPR order. In fact child was for full
resuscitation and this was documented on Advance
Care Plan. (report 61)

Many incidents caused distress to patient, families
and staff, with organisational consequences such as
use of ambulances and inappropriate hospital admis-
sion causing pressures on resources. The untoward
outcomes most commonly described were inappro-
priate CPR attempts present in 19 reports (27%).
Together these are encapsulated in this example:

Resuscitated and return of spontaneous circulation
after 15 min, intubated and ventilated and
transferred up to critical care. Family very angry
that despite highlighting medical alert bracelet that
stated patient has a living will nothing done and
patient ended up in a situation which they would
not have wanted. (report 31)

Our overarching analysis is integrated and synthe-
sised in a driver diagram (figure 2) mapping data-
driven theories (primary and secondary drivers arising
from our analysis) to change ideas with matched
evidence-based interventions (when possible). The
strength of interventions is graded using the USDVA
classification.

DISCUSSION
ACP is advocated to align care with patients’ wishes
and prior healthcare decisions. Our national-level
analysis of patient safety incidents demonstrates defi-
cits throughout ACP processes including problems
with creation, communication and application of ACP
to guide decision-making. This is the first analysis of
patient safety incidents relating to ACP. The study
provides empirical evidence of the suboptimal and
unsafe care received by patients as a result of issues
concerning ACP.

In around a quarter of incidents analysed, lack of
ACP creation contributed to an incident. Low uptake
of ACP is a well-described problem for which there are
many postulated causes. Barriers include a perceived
lack of skill by clinicians, fear of depriving patients of
hope, confusion over responsibility, timing and initi-
ation of discussions. Lack of public awareness and
societal reluctance to talk about death could also be
factors. Interventions aimed at increasing uptake of
ACP can be effective, the most successful are complex
interventions that address multiple barriers. Any
initiative to improve ACP must ensure relevant staff
have the confidence to initiate, create and enact ACP.
Lack of accurate and timely communication of ACP
was the most commonly reported incident which
is consistent with previous work. Patients in
the last phase of life often have multiple pathologies and
complex needs. They are likely to seek care from
numerous healthcare providers. A reliable system for
communicating ACP across services is key to providing
safe, effective care. Electronic palliative care coordi-
nation systems (EPaCCS) have been advocated as
a solution for this. There are many EPaCCS inter-
nationally, varying considerably in format and
scope. ‘Coordinate my Care’ in London reports a large
majority of patients dying in their preferred place of
care and suggests a reduction in hospital admissions.
Studies show EPaCCS can improve data sharing
and influence care decisions. However data sets are
small and concerns remain about the lack of high-
quality evidence for the efficacy of EPaCCS which
can be burdensome to use with technical issues and
duplication of work. Systems for communicating
ACP information across providers should be robustly


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evaluated with the aim of developing systems that balance data security, accessibility and usability, and are integrated with existing systems.

Most existing studies focus on improving uptake and documentation of ACP, with a paucity of evidence looking at application and impact on clinical decision-making. ACPs may not be followed even when adequately communicated. From our analysis of incident reports, a lack of staff understanding of ACP is a key contributory factor affecting all stages of ACP. Previous studies have demonstrated a lack of confidence and knowledge about ACP among GPs affecting the initiation of ACP and among paramedics affecting interpretation of ACP. Our study adds further evidence demonstrating that lack of staff understanding of ACP can contribute to unsafe and inappropriate care. More research is needed to understand how to enable clinicians to create and use high-quality ACP to guide decision-making. Interpretation and application of ACP is complex and requires higher-level meta-cognitive skills, confidence, experience and emotional intelligence. Fear of medicolegal consequences of making the wrong decision regarding life-sustaining treatments is justified by high-profile cases in which healthcare professionals have been punished for not attempting CPR, which was felt to be futile. Improving timely access to advice in support of these complex decisions for staff is critical, but potentially a cultural shift is also required to empower staff to use their professional judgement and to protect them when they do so. ACP is an inherently human-dependent process, so it is critical that interventions tackle these human-dependent concerns as well as the systems involved.

Given the patient impact of ACP incidents the low volume of reports related to ACP does not necessarily indicate that ACP is a relatively safe process. Under-reporting is a recognised issue with safety incident reporting and thus these reports are likely to represent the tip of an iceberg. Most NRLS reports are received from acute/general hospitals which may have impacted on the population of incidents from which our sample was selected since we would expect most ACP incidents to occur in community settings. Another possibility is that ACP is not widely perceived as a patient safety issue. Patient safety in palliative care has had less scrutiny and is less clearly understood than in disciplines such as surgery or critical care. In the UK the National Institute for Health and Care Excellence first published guidance on ACP in 2004. The National End of Life Care strategy (2008, updated 2014) was a crucial policy publication increasing interest in ACP. Our study period covers 2005–2015. This study contributes an important analysis of incidents faced by vulnerable people at a time of evolving policy and increasing use of ACP, highlighting front-line challenges in ACP implementation and extending what is known by deepening understanding of how and why unsafe care is occurring. The full impact of continued publication of policies and guidance for ACP remains unknown especially as later policy documents appear to assume that ACP creation and communication have occurred effectively and focus on ensuring ACP is enacted.

Our analysis has extracted valuable learning about how failures in ACP can cause harm and distress and identified principles that are generalisable. The methods used for this work further contribute to the literature by offering a replicable approach for analysis of other local or national databases. This evidence can be used to illuminate the design of solutions; drawing on our analysis in such designs will bring about a greater chance of success.

Conclusion

Breakdowns in ACP occur due to lack of completion, lack of communication or lack of trust at the moment the enactment is required. Incidents occur in all three of these sequential elements of ACP because of human-dependent issues impacting on the entire process; these issues relate to wider societal concerns, beliefs and misconceptions about medicolegal frameworks, organisation of services with front-line professionals lacking decision-making capacity and the complexities of actual processes in clinical situations which inevitably do not follow linear descriptions of intended processes in policy.

Further work should focus on measuring the impact of improvement activities targeting ACP human-dependent and systems elements to improve the safety of care for patients in the last phase of life. Our findings question whether it is possible to develop strong system interventions to ensure safety and quality in ACP without significant improvement in human-dependent concerns such as patient, carer and professional understanding of ACP and the trustworthiness of enacting prior ACP. Achieving this should be explored in local contexts alongside systems development for recording and accessing ACP documents so that quality as well as quantity of ACP usage improves. Rigorous evaluation of ACP initiatives is needed, with dissemination of results to ensure the safest, highest quality and most effective models can be replicated and adapted to local contexts.

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